

# **A Disabled Person's Perspective on Pre-Natal Screening 1999 Alison Davis**

It seems to me that every other day, newspapers report yet another "exciting breakthrough" in pre-natal screening. It is always unclear who is supposed to be "excited" by it, and why, but a common reaction among people with severe disabilities is the cold inner grip of a feeling never far from the surface - that we are tolerated only on sufferance, and that society would really prefer us to be quietly eliminated.

I will look at several aspects of pre-natal screening from my own point of view as an adult who has severe spina bifida and is a full-time wheelchair user. I am fully aware that about 85% of babies who would otherwise grow up to be like me are now aborted, following a positive pre-natal screening result.<sup>1</sup> I will consider:

- a) the purposes and consequences of pre-natal screening,
- b) pressure on women to accept screening and eugenic abortion
- c) political, social and economic considerations,
- d) the role of midwives
- e) the views of people with disabilities.

## **a) The purposes and consequences of pre-natal screening**

The popular media has often obscured the real purpose of screening. Dr. Miriam Stoppard, wrote in comfortable terms that:

There are many safeguards ... ensuring a healthy baby. Some procedures, such as ultrasound scans and amniocentesis, may seem quite daunting to first-time mums, but don't be intimidated by them ... a routine scan can ... exclude fetal abnormalities, such as spina bifida<sup>2</sup>

The impression given is that screening itself will "ensure" that the baby is "healthy" which of course it does not. If it is done to detect and treat a medical condition, or to ensure a safe delivery, it has a good purpose. However, all too often, its real purpose is to detect disabled babies in order that they may be aborted.

There is a clear expectation that abortion will follow a positive screening test. I have lost count of the number of times I have read of women who apparently "had to" abort a

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<sup>1</sup> "Whey we need flour power" by Annabel Ferriman. The Independent 1/12/98

<sup>2</sup> "Keeping an eye on mum" by Miriam Stoppard. Page 31 The Mirror 20/08/98

disabled baby. The disc jockey Jo Whiley, for instance, mentioned that her mother had "no option" but to abort a baby with Cri du Chat Syndrome.<sup>3</sup>

A father of a baby aborted on the grounds of disability said:

"Our Consultant guided us through the decision making process ... she made it EASIER to say yes (to the abortion) knowing it was the only way"<sup>4</sup> (original emphasis)

Clearly "choice" is not what it might seem, when "the only way" is to "choose" the death of the child. The choice women are given is frequently Hobson's choice these days.

## b) Pressure on parents to accept screening and abortion

In spite of all the reassurances of "informed choice" very often women report that they have experienced deliberate pressure to accept the doctor's point of view. For instance a doctor was reported as saying to a woman who had a child with Down's Syndrome,

"So you will be having the tests, seeing you have a handicapped child already". She refused and he looked up in horror and said "but of course you must! You can't have two handicapped children!"<sup>5</sup>

Often this pressure can be quite subtle, as the following piece makes clear. The General Practitioner magazine carried an article about a doctor asked to consider an hypothetical case concerning "Fiona" who has declined an abortion for spina bifida. He says:

"I would explain the potential problems of continuing the pregnancy and explore how Fiona would cope .. it is essential that she is fully aware of the potential risks (of continuing the pregnancy) in order to arrive at an informed decision ... she has the right to decline an abortion even if there is a substantial risk that the child might be seriously handicapped when born"<sup>6</sup>. (emphasis added).

One wonders if we would be quite so rigorous in describing the "potential risks and problems" of having an abortion.

Sometimes also, doctors will blame women who have a disabled child after refusing screening. My friend Sandy has a ten year old son Michael, who has Down's Syndrome. One night when he was still a baby, he had a bad cough and she eventually called out the

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<sup>3</sup> "Why I fear for my next child" by Moria Petty. Page 23. The Times 9/4/98

<sup>4</sup> "Antenatal screening for Down's Syndrome" by Helen Statham and Wendy Solomou. Page 1862 The Lancet 5/12/98

<sup>5</sup> "The baby dilemma that won't go away" by Julia Llewellyn Smith. The Times 30/01/96

<sup>6</sup> "Amniocentesis result causes confusion" Adapted with permission from "The human rights, ethical and moral dimensions of healthcare: 120 practical case studies ed. Pierre Cueur and Jean-Pierre Massue Page 46 General Practitioner 04/09/98

doctor. His first comment was "Why didn't you have the tests?" said within hearing of Michael.

The usual response I have when telling this story is that the child "wouldn't have understood". However, I can still remember people discussing my disability when I was very young and confidently pronouncing that "Of course, she can't understand yet".

### c) Political, social and economic considerations

I believe that much of the enthusiasm for pre-natal screening and eugenic abortion stems from an unconscious fear of, and prejudice against, people with disabilities. An associated and very strong factor is the idea that eliminating those with congenital disabilities "saves money".

The social prejudice against those with obvious disabilities is made clear by the discrepancy in the words used to describe able bodied and disabled babies in the womb (the able bodied dubbed "perfect" or "health"; the disabled, by inference uniquely "unhealthy" and "imperfect") and disabled people inside and outside the womb. In recent years, descriptions of born disabled people have become a trap of political correctness for the unwary. We have to speak now of people with disabilities of "learning difficulties" and, arguably reaching the realms of the ridiculous, the "physically challenged".

The words used to describe babies in the womb with the very same disabling conditions reflect more closely, I think, what society really thinks of us. Then we read of "abnormal fetuses", "malformation" and "defective" and "deformed babies". I fear one cannot have it both ways. Either I am a "defective adult" or a "person with a disability". Using terms selectively smacks of hypocrisy.

Some members of the medical profession go to extraordinary lengths to protest that screening and abortion are not offensive to born disabled people. Prof. Nicholas Wald, for instance, has said that "the idea that they are discriminatory is complete nonsense" and he argues:

"It's like suggesting that if we try to prevent strokes it will have an adverse effect on people who have strokes. The idea that spina bifida and Down's Syndrome people are worth less because of screening and abortion programmes is preposterous and incorrect."<sup>7</sup>

He hasn't asked us of course. And it would appear that he is ignoring, willfully or otherwise, the fact that preventing strokes should not involve killing those who have been affected by them.

We have to consider also the price of screening programmes, both economic and human. They are very often justified on the grounds that detecting and "eliminating" an affected

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<sup>7</sup> "Truth and trouble with scans" by Annabel Ferriman. Page 10 The Guardian 24/09/96

baby costs less than caring. For instance The Times reported in April 1994 that the cost of supporting a child with Down's Syndrome was £120,000 compared with a cost of £38,000 for each disabled baby detected by screening and aborted.<sup>8</sup> The BMJ made a similar analysis in July 1997. The title of the article was telling - "Screening for Fragile X is cost-effective and accurate"<sup>9</sup>

I note in this respect that no mention is ever made of the cost of £3,450 per week for keeping a young offender in a local authority secure unit, or that the 2,500 youths aged 15-17 currently in custody have cost the taxpayer £75,000 per head.<sup>10</sup>

There is also the huge human cost to consider, which does not consist only of the approximately 2000 disabled babies aborted every year after positive screening results. There is a miscarriage rate of about 1% with both chronic villus sampling and early amniocentesis,<sup>11</sup>

The General Practitioner (24/07/92) also noted that "A new survey reveals that more than one in ten antenatal diagnoses of serious malformations are completely wrong."<sup>12</sup> This includes one in forty spina bifida diagnoses and one in 1.5 cases of duodenal atresia. This, of course, means that some non-disabled babies will be aborted in error.

Dr. Josephine Venn-Treloar notes:

Studies show that detecting and eliminating two Down's Syndrome babies by screening programmes costs on "normal" baby who succumbs as a result of the programme. This "trade off" is considered to be cost-effective; costs of detecting are thought to be less than the "cost" to society of a Down's Syndrome person. The loss of one "normal" baby is thought to be a price worth paying.<sup>13</sup>

In addition to these completely unnecessary deaths, the "price" of these eugenic screening programmes also includes unnecessary disability. There were reports in 1995 of 40 originally non-disabled children rendered disabled by pre-natal screening tests. This included Benjamin Sinclair-Wilson, who has cerebral palsy, and Mishka Parnell, who was born paralysed, blind and deaf and subsequently died before her third birthday. In both cases the amniocentesis needle had pierced the unborn child's brain.<sup>14</sup>

A large factor in the general enthusiasm for screening is that disability is presented as a "label" and not as a condition possessed by a human being. In June 1997 a Research Centre in Bristol organised a conference on genetic screening at which Theresa Marteau,

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<sup>8</sup> "Hidden cost of testing for Down's" by Dr. Kieran Sweeney. Page 15. The Times 05/04/94

<sup>9</sup> "Screening for fragile X is cost effective and accurate" by Caroline White Page 208. BMJ 26/7/97

<sup>10</sup> "Detained youths cost taxpayer £75,000 a head" By Richard Ford. Page 8. The Times 14/12/98

<sup>11</sup> "Randomised study of risk of fetal loss related to early amniocentesis versus chorionic villus sampling" by K. Sundbery, et al. Page 697. The Lancet 6/9/97

<sup>12</sup> "One in 10 antenatal diagnoses proved false" by Helen Reilly page 15 General Practitioner 24/7/92

<sup>13</sup> "Nuchal translucency - screening without consent" by Dr. Josephine Venn-Treloar Page 1027 BMJ 28/3/98

<sup>14</sup> "Will this test harm your unborn baby?" by Paul Fuller page 58 The Express 23/11/98

Professor of Health Psychology at Guy's and St. Thomas's Medical School spoke. She described a study of 84 consultations with parents prior to pre-natal screening for Down's Syndrome. Only two of the consultations included any information about Down's Syndrome and those two were inaccurate.<sup>15</sup>

On one occasion I received a telephone call from a distraught woman who had been given 24 hours to decide whether or not to abort her baby, who had spina bifida. She said "no one will tell me what spina bifida is".

Even when members of the medical profession do give information about disability it is rarely objective. The difficulty, largely, stems from the fact that the doctor or midwife is describing a disability and not a person who has the disability. It is rather like trying to describe a short-sighted person by stated the prescription for his glasses. Spina bifida is what I have, not what I am. Nevertheless, parents are asked to decide on life or death for a human being they know nothing about except that s/he has a particular condition.

Even then, I fear, medical people are likely to underestimate what is possible, or speak in very negative tones about what is likely not to be possible. A friend of mine, Sarah Thomas, was told, when pregnant, that her son Luke, diagnosed as having spina bifida and hydrocephalus had "a head like a banana" and "part of the brain missing" and would be unable to do anything much for himself, if he lived, which was considered unlikely. She was strongly advised to abort, and called "awkward" and "unrealistic" for refusing. The hospital even took to phoning her up at home in the hope that she had changed her mind and would now do the "sensible thing". Luke is now 9 years old, a full time wheelchair user and doing well in a mainstream school. His head, you will be pleased to know, is NOT "like a banana" and he leads a very full life, currently learning dancing. His mother says his two able bodied brothers are far more trouble than Luke - and she means it.

I have many disabled friends who have confounded doctors' early estimations of their abilities. I shall mention just two:

Peter has spina bifida and his mother was told to "leave him in the hospital, go home and have another baby" as he would not live beyond three months; he is now 42.

Glenis has Ebstein's Anomaly, and her mother was given a prognosis of 5 years; she is now 55.

Some babies clearly will die very young, but I really do not understand why this is considered to be a good reason to deny them what little experience of life they will have. It seems sometimes that the medical profession wants it both ways. In the early days of pre-natal screening, doctors were telling parents of babies with Down's Syndrome to abort because they would not live very long. Now they can live close to an average life-span, doctors are telling parents to abort because the child will not die young.

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<sup>15</sup> "Considered Choices" by Paul Williams Page 12. Speak Out July 1997

We have heard much, recently, about discrimination against people with Down's Syndrome in, for instance, heart surgery. I have personal experience of this as a couple of years ago I managed to find a surgeon prepared to operate on a little girl called Maria, who was then 8 years old, and whose heart problem had been declared "inoperable" at a famous London hospital. Her parents had been told she would deteriorate and die in her early teens. The surgeon she subsequently saw operated on her and she is now fit, well and 11 years old with many years ahead of her. She is not the only child I know of who has been refused surgery because of her disability. Many people think this is appalling, but it is only the logical extension of the search and destroy mentality of pre-natal screening. If medical staff, including midwives, are willing to kill a disabled child before birth, why should they want to take steps to prolong the lives of similarly disabled children after birth.

#### **d) The role of Midwives**

I have been interested to discover that midwives can be involved in the eugenic abortion process very closely and at all stages - before pre-natal screening, during the decision whether or not to abort, and also after abortion. Of course, one cannot ascribe to a whole profession the views of individuals. Nevertheless, I have noticed, in reading articles on life issues in the mainstream medical Press over the last eighteen years, that many references to midwives and their organisations have displayed a less than neutral stance on this issue.

In 1987, for instance, the Royal College of Midwives opposed David Alton's Bill, which aimed to reduce the upper limit for abortion to 18 weeks, because they, along with other Royal Medical Colleges apparently regarded it as "discriminatory against women such as those carrying an abnormal fetus" . (Times 3/12/87). Similarly in March 1988, Midwives Chronicle and Nursing Notes noted that the RCM felt that with Alton's Bill "the removal of the availability of abortion above 18 weeks would restrict the potential benefit of screening and hence is unacceptable". This clearly suggests that pre-natal screening to facilitate eugenic abortion was seen as an equivocally good thing.

Coming forward in time, in 1997, the Daily Mail (10/5/97) somewhat encouragingly, reported that a growing number of midwives were refusing to take part in late eugenic abortions. It noted the horror of many midwives at the RCOG advice to midwives precipitating abortions to ensure that the fetus was born dead, to avoid being sued if the baby were born alive. Their guidelines described techniques such as giving a lethal injection, which reportedly many midwives felt was contrary to both their consciences and their training.

Rather less encouragingly, The Times (24/01/98) carried an article pointing out that the same midwife, during the same shift may find herself trying to save the life of a "desperately wanted but very premature 24 week gestation baby" and also administering drugs to abort a baby of the same age, unwanted because s/he had an obvious disability. The article described in some detail the aborting, by a midwife, of a baby with my

condition - myelomeningocele spina bifida, and noted that the midwife's justification for doing it was "supporting the mother" in her "difficult decision".

"Supporting a mother" sounds very positive, but of course, it depends what the mother is doing. For instance, no one would "support a mother" in her decision to batter her children. I would suggest that in order to "support" a woman aborting a baby in such a practical way, one would inevitably have to also "support" her decision to kill the baby. It would surely be impossible to precipitate an action knowing it will result in the death of a human being, if one did not somehow feel that causing the death of such a human being was a legitimate course of action.

Barbara Rothman, in her book *The Tentative Pregnancy* noted that most midwife counsellors advocate "non-directive" counselling but she

"they admit that counselling would become more directive, that is, leading the couple towards TOP (Termination of Pregnancy), in response to the severity of the abnormality detected". (1998)

During pregnancy women are very vulnerable - to being told what they may not want to hear, to being told inaccurate or biased information, and to being "counselled" into "choosing" an abortion. This was certainly the experience of my friend Sue Edwards, who has a four year old daughter, Evangeline, who has TAR Syndrome.<sup>16</sup> When Sue went to the hospital for her booking appointment she made it clear that she did not want any pre-natal tests, and insisted that it was recorded on her notes that she did not want to be given any information about possible disabilities in her unborn child. As things turned out, this written instruction in her notes was either ignored or over-ridden.

She had a first scan to establish her dates and was told (remember, against her express wishes) that the baby was not going to survive the pregnancy and that she should abort as soon as possible as "the easiest option". She refused, and asked for a second opinion.

Over the next few months she saw many different "specialists" and got conflicting diagnoses including :

1. Edwards Syndrome
2. A rare genetic condition with no name which would mean the baby would be either born dead or live only a few hours.
3. Another nameless syndrome which would mean the baby would live to be about 5 years old and then die.
4. Just short arms with no other disability
5. TAR syndrome (shortened limbs and problems with blood clotting).
6. A chest so narrow and compressed that the labour would kill the baby.

This last diagnosis was the information she had when she went into labour, and one can only imagine her emotions during that time. Fortunately, Evie survived, and is now a

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<sup>16</sup> Thrombocytopenia Absent Radius Syndrome

very bright, very perky, severely physically disabled child. Sue, however, was needlessly worried all through her pregnancy and during labour when all she wanted was to love and accept her baby.

Sue is, perhaps unusual in her positive outlook on disability, and determination to accept her baby unconditionally. Other women may well react in a different way to the stresses of pre-natal screening. *Obstetrics & Gynecology* (11/88) (*Q Midwives Chronicle and Nursing Notes* 7/94) reported a study showing that

"women suppressed feelings of attachment to the baby and had high levels of anxiety until normal results had been given"

The article concluded that,

"where women experience high levels of anxiety in the 2nd trimester and suppress attachment to the fetus (of whom they are becoming increasingly physically aware) this can have profound psychological ramifications."

In an enthusiasm for eliminating disabled babies, it seems that many women are being denied the chance to bond with their baby until s/he is declared "normal". The possible effects on the later relationship between mother and baby (if s/he is permitted to live) are incalculable but profoundly worrying.

Very often too, the psychological effect on women of eugenic abortion is overlooked. A *BMJ* study (1985 *Q Nursing Standard* 12/93) found that 77% suffered "acute grief" and in some of these women serious psychological illness followed. The organisation SATFA (Support Around Termination for Fetal Abnormality - now called Antenatal Results and Choices) quotes a parent after having a eugenic abortion saying,

To lose a child is bad enough, but to be the executioner is something you have to live with for the rest of your life.

Photographing the aborted baby, taking hand and foot prints, dressing her, keeping a lock of hair, and all the ways in which the medical profession try to "help" cannot obscure the fact that a baby has been caused to die because s/he was not considered good enough or "perfect" enough or loveable enough to be allowed to live.

Many disabled people are profoundly concerned at the role of midwives in killing babies with disabilities. This is perhaps particularly so for disabled women who are themselves pregnant and under a midwife's care. It is disconcerting to realise that the person who is caring for you and your baby may that very day have been involved in killing another baby, solely because s/he would have grown up to be like you.

I strongly believe that it is not possible to have a positive attitude towards a minority group while one is simultaneously directly involved in their deliberate destruction.



## **e) The effect of pre-natal screening on born disabled people.**

Many disabled people feel justifiable anger at the thought that our society is spending millions on programmes whose purpose is to detect and eliminate us. For instance Tracey Proudlock, who has spina bifida and is the mother of two children spoke at a study day at Queen Charlotte's Hospital, London organised by the congenital malformations register. In seconding a motion against pre-natal screening by the Director of the Genetic Interest Group Mrs. Proudlock said,

"A civilised society is judged not on how successful it is at screening out disability, but how it accommodates difference".<sup>17</sup>

I feel strongly that the way screening programmes are reported implies that disabled babies never grow up, and that "a spina bifida" (a term by which I am frequently identified by doctors) cannot possibly be just another citizen leading an average sort of life. I am both amazed and amused by the common assumption that I don't have to pay taxes because I am disabled. I wish!

I know that I am an ordinary human being, who simply has disabilities which are more obvious than those of the majority. I believe my life - every human life - to be of infinite value, not valuable only if it achieves a particular "quality".

Let me stress now that I am most definitely not saying that I should be allowed to live because I can do or achieve particular things. My life has been full and varied, and I have had my share of highs and lows, a few of which are attributable to my disability. The greatest joy of my life today is supporting a centre for 83 severely disabled children in India. I write to them and visit them regularly, and I love them as fiercely and protectively as if I had borne them myself. They have none of the advantages I have and many of them can only crawl. But it would be a brave person who tried to tell me they would have been better screened out of existence.

Members of the medical profession often justify screening and abortion for spina bifida to me on the grounds that "you are exceptional".

**My answer is twofold:**

**Every human being is exceptional, unique, beyond price.**

**and**

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<sup>17</sup> Association for Spina Bifida and Hydrocephalus - Link - "Two screen or not to screen?! Page 17. Aug - Sept. 1995

If they had had their way 44 years ago, I would not have been exceptional - I would have been one of the nameless "defective fetuses" that they consign to the medical waste bin every year, all in the name of "choice".

Alison Davis 30/03/99